



Peter Mac
Peter MacCallum Cancer Centre
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Neuroendocrine carcinoma of the cervix: An exploratory study of the prevalence of emotional and psychological distress levels and needs for support from the patient experience

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Neuroendocrine Tumours (NETs)

- Occur in various organs
- Express biochemical marker: Synaptophysin, Chromogranin, Neurone Specific Endolase (NSE) + CD56
- Range from low to high-grade tumours (Higher KI67 = more aggressive)
- Prognosis is dependent on the histologic subtype and site of origin
- Incidence increasing

- Small-cell and large-cell cervical NETS
 - Extremely rare (2%) and highly aggressive
 - Share similarities with small-cell lung cancer
 - Have limited treatment options
 - Multimodality approach including platinum based chemotherapy and etoposide
 - Poorer prognosis

(Burzawa, Gonzales & Frumovitz et al 2015)



Living with a rare cancer

- Emotional distress
- Anxiety
- Worry
- Uncertainty about treatment success
- Fear relating to prognosis
- Fear of recurrence

(Zaid, Burzawa & Basen-Engquist et al. 2014)



The project aims

Primary aim

- To explore the reported experiences and prevalence of emotional and psychological distress in patients with a diagnosis of a rare gynaecological cancer with a poor prognosis both during and after treatment

Secondary aims

- To examine the referrals for psychological support
- Reflect on the clinical experience of caring for women with neuroendocrine cervical cancer
- To determine the need for supports specifically catered to this cohort of patients



Methodology

- Retrospective audit
- Existing prospective database of patients with a gynaecological cancer treated with radiotherapy
- Corresponding electronic medical record
- 2 nurse coordinators
 - Retrospective review of medical the notes
 - Reflective review of the entries noting common themes



Participants

- Women with cervix cancer
- Inclusion criteria
 - a histological diagnosis of small- and large-cell neuroendocrine tumour (cervix NET)
 - treated with radiotherapy at Peter Mac between 1998 + 2014
- Exclusion criteria
 - Electronic notes unavailable
- Participants de-identified



Demographics

- 31 eligible patients
- Mean diagnosis age of 49 years (range 22-92 years)
- Confirmed diagnosis:
 - 20 small-cell NET
 - 6 large-cell NET
 - 2 mixed
 - 3 small-cell cervix without confirmed NET component recorded in notes
- 18 diagnosed with early stage disease
- Patient current status:
 - 13 alive
 - 17 deceased
 - 1 lost to follow-up



Prevalence of psychological distress

- 71% (n=22/31) had documented needs for professional emotional support
- 32% (n=10/31) had a record of psychological morbidity related to fear of recurrence
- Patient's still alive reported high levels of distress
- Greater than 5/10 on distress thermometer



Referrals for psychological support

- 77% (n=17/22) accessed professional supports
- 13% (n=3/22) declined when offered
- 9% (n=) 2/22 had no record
- Majority accessed psychology
- High prevalence and high requirements primarily related to fear of recurrence



Geraldine

- 63 year old
- Lives with husband
- 2 adult children
- Retired administrator
- Diagnosed with locally advanced large cell neuroendocrine cervical cancer
- Completed multimodality therapy - surgery chemotherapy and radiotherapy



Risk stratification for emotional distress

- High risk disease (poorer prognosis)
- Rare cancer
- Impact of treatment
- Follow up primarily in hospital – emotional assessments
- Assessment for support



Supports available in Australia



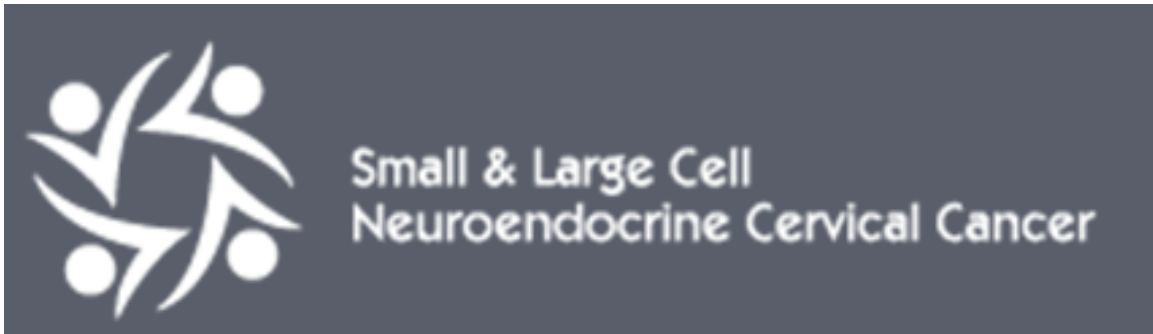
Cancer Connect

Telephone and online supports for
gynaecology

Online Cancer Connections



Support in the US



- 3 patients still alive have accessed an American on-line support specific to cervical NETs



Conclusions

- High level of distress and fear of recurrence reported in this population - may reflect the lived experience of living with a rare cancer with a poor prognosis
- The information gained is anticipated to be beneficial for a wider health community
- Needs assessment recommended and referral to existing supports when required
- Recommendation that non-government organisations and the gynaecology oncology community consider the development of national supports specific for women diagnosed with a cervix NET

